

# IMMUNIZATION REGISTRY FOCUS GROUP STUDY

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Bilingual Hispanic Higher education

Tucson, Arizona

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## SECTION 1: GENERAL IMMUNIZATIONS AND HEALTHCARE

### I. Prevention

Diseases mentioned:

- Polio
- AIDS
- Asthma
- *E. coli*
- Diabetes
- Cancer
- Hepatitis

### II. Immunization

#### A. *Reasons not to get vaccinated*

- Fear of side effects
- Trauma for the child
- Misinformation
- The belief that the illness was eradicated

#### B. *Reasons to get vaccinated*

- To avoid getting ill
- So child will not be as ill if he or she contracts the disease

#### C. *Ways parents are reminded of vaccine schedule*

- Public announcements (radio and television)
- Reminder calls or letters from doctors and/or clinics
- Keeping the immunization record card given at the birth of children
- Vaccination campaigns like those in Mexico (radio, television, billboards, newspapers, loud speaker trucks driving through neighborhoods)
- Reminders from schools

- Reminders from insurance companies

**D. *Methods of easier tracking***

- PSAs about when to get vaccines
- State should give free vaccinations
- Put announcement in newspaper
- A reminder system
- Reminder from doctor (i.e., a phone call or letter)

## **SECTION 2: IMMUNIZATION REGISTRIES**

### **I. Initial reactions to the idea of a registry**

***Positive reactions:***

- Registries will provide for retrieval of information when other records are lost.
- The registry would simplify the record-keeping process.
- It will centralize information. (Note: Respondents said this was important for families that move around.)
- The registry would prevent vaccinating a child twice for the same disease.

***Negative reactions/concerns:***

- Parents who do not want to vaccinate their children may feel discriminated against
- Information will not be confidential.
- Information might be registered incorrectly.

***Other concerns:***

- Would the registry include adults as well as children?
- Who will have access to the registry?
- What is the cost for the individual and for the taxpayer?

### **II. Content of the registries**

***Initial reactions to the type of information typically in a registry***

- Bilingual respondents were less apprehensive and noted fewer concerns than the less educated monolingual respondents.
- Respondents suggested that the following information be included in the registry:
  - Drug allergies and possible cross-reactions
  - Name of the person who administered the vaccination
  - Names of both father and mother

***Reactions to including home address and phone number***

- Most respondents felt this information was important so they could receive information and reminders.
- A few respondents said they preferred to be contacted only by mail, not by phone.

**C. *Reactions to including parent or child Social Security number***

- Most respondents felt this information would eliminate confusion among children who have the same names.
- Many respondents felt that having the SSN on file would be helpful in case of emergency.

***Reactions to including healthcare members enrollment (WIC, Medicaid numbers)***

- Respondents were positive about including Medicaid numbers as similar information is already noted there.
- They did not comment about WIC.

**III. Access**

***Who should have access***

- Doctors
- Emergency personnel
- Parents
- Day care and school administrators (for emergencies)
- Insurance companies
- When probed about researchers and insurance companies having access, there was generally little concern among respondents.

### ***Who should not have access***

- Bilingual respondents were not as concerned as monolingual respondents about the possibility of the registry providing information to former spouses.

### ***C. Reactions to idea of linking registry by computer to other health information systems***

- In general participants were positive about this idea, but expressed concern about accuracy and “linking too many systems.”

## **IV. Consent and Inclusion**

### ***Reactions to “opting out” option***

- Respondents liked having a choice about the registry.
- They felt this was the best plan for children because it made the process somewhat difficult for parents who wanted to exclude their children.
- Respondents said this option protected children if information was lost in the mail.

### ***Reactions to “consent” option***

- Respondents said that this option was less likely to protect children whose parents might not respond due to neglect or forgetfulness.

### ***C. Reactions to “automatic” option***

- Most respondents disliked this option. They said it would make them feel mandated to be in the registry and that they had no choice.
- Respondents said, however, that this option would ensure the safety of their children.

## **SECTION 3: WRAP UP AND CLOSING**

### **I. Most important benefit(s) of registries**

- Fast, easy access when information has been lost or a child changes doctors
- Warnings about adverse reactions
- Education of parents about immunizations
- Convenience

- Reduced possibility of receiving the same vaccine twice
- Reminders of when vaccines are due

## **II. Greatest concern(s)/biggest risk(s)**

- The possibility that information in the registry will be incorrect
- Breaches of confidentiality
- Technological failures (e.g. Y2K computer problems)
- Liability for parents who do not want to vaccinate their children
- Possible denial of medical benefits for those who may choose not to vaccinate their children
- Respondents express little concern when probed about custodial, government, and immigration issues.

## **III. Influence of healthcare provider in decision to participate in a registry**

- About half of the respondents said that their physicians' advice would not influence their decisions to enroll in the registry.

## **IV. Suggestions/comments to people who are responsible for how system works**

- *The registry is a very good idea. Make sure the information is accurately updated. Parents should have access to registry information at all times.*
- *It's very convenient for everyone. It's easier to follow up on vaccinations. I hope we get it sometime.*
- *I would like for you to make sure that information is put in accurately so no mix-ups will occur in the future.*
- *The list should be comprehensive and constantly updated. Parents should have access and hard copies should be provided.*